Federal Pre-Budget Submission 2022-23

January 2022

WHO WE ARE

Health Issues Centre (HIC) is Victoria's recognised peak consumer health advocacy body. We are registered as a charity and have been operating for over 35 years.

HIC was formed to provide a voice for consumers and shape human-centred design of health services.

We champion the voices of everyday people in all aspects of our healthcare system and represent the millions of Australians receiving healthcare.

We continuously engage with health consumers to:

- ***Policy*** – Advocate on behalf of health consumers, particularly those who currently have no influence on the decisions that define public health policy.

- ***Service improvement*** – Identify emerging health needs and gaps in service delivery to ensure that consumers play a central role in health service design that meets their needs and delivers quality and safety improvements.

- ***Health literacy*** – Deliver a range of consumer training courses including Australia's only nationally accredited consumer training. We have trained 3,000 people in the last five years alone.

SUMMARY OF RECOMMENDATIONS

1. **Invest in consumers' and researchers' capacity to collaborate as partners in research, through the new National Health and Medical Research Strategy [$1.2 million over three years]**

2. **Invest in digital infrastructure through the draft Australian Digital Health Strategy to improve equitable access to digital health [$2 million over two years]**

3. **Support health consumers and health practitioners by funding HIC to deliver its training for consumers and services online nationwide [$400K over two years]**

1. **Invest in consumers' and researchers' capacity to collaborate as partners in research, through the new National Health and Medical Research Strategy [$1.2 million over three years]**

The opportunity

The pandemic has highlighted the critical role medical research plays in our health and wellbeing, but a government investment is needed to better-enable consumers and researchers to collaborate.

It is acknowledged that consumer involvement in research leads to better, translatable outcomes that improve healthcare. These benefits and the importance of consumer input into health and medical research are well-documented.[1]

Moreover, there is growing institutional recognition of the importance of consumer input into health research (e.g. NHMRC[2]; MRFF[3]).

The NHMRC has previously committed itself to:
- 'Deliver targeted calls for research that respond to unmet or emerging health needs and reflect national, state and territory, and consumer and community priorities.'
- 'Engage with the Australian community and consumers on health care and medical research, including increasing community involvement in research and access to the results of research.'

'Consumer-driven research' is the first-listed priority in the new draft *Australian Medical Research and Innovation Priorities* (November 2021):
- "1. Consumer-Driven Research. Research that is driven by meaningful consumer involvement and partnerships, to incorporate priorities, needs, values and experiences to deliver fit-for-purpose outcomes that can be adopted by consumers, carers, healthcare professionals and other end-users."[4]

Critically, as consumer input is increasingly valued, recognised and mandated, both researchers and consumers require support to embed this into research practices. This includes when prioritizing research activity, designing research, interpreting results, communicating findings and ensuring that research is translated into better public health outcomes.

What are we asking the Government to do?

Fund HIC to deliver a package of measures to foster a partnership relationship between consumers and researchers.

To achieve a true consumer-researcher partnership, government investment is needed in consumers, not just research institutions to better prepare consumers to engage in the research process.

To prepare consumers to be partners in research, HIC would:
- Provide recruitment and mentoring of consumers as potential research advisers/participants
- Establish a pool of "research ready" consumers for emerging research projects
- Provide skill-specific training to consumers for the various stages of the research cycle

To support researchers, HIC would:
- Train researchers on the principles and in the practice of community engagement

- Provide Consumer Engagement support packages i.e. develop and manage consumer engagement programs for individual research projects

To foster a research partnership between the research community and consumers, HIC would:
- Develop a standard set of principles that defines the mutual obligations, rights and roles of researchers and the communities that are the objects or beneficiaries of research
- Ensure that research protocols (including ethics frameworks) balance consumer access and protections to optimise participation.
- Establish an institutional capacity to advocate for the consumer perspective in research strategy and planning.

Consumer input improves research outcomes, but support for consumers and researchers is needed if we are to develop a truly collaborative partnership model.

We were pleased to see the Minister for Health announce 'Vision 2040 – National Health and Medical Research Strategy' in December 2021, and anticipate that the support outlined above for consumers could form part of the Strategy.

Likely impact

- **Improve research outcomes**
  - Better quality studies
  - Better translation of findings into practical solutions and community benefits
  - Improved recruitment and retention of research study participants
  - Improved research dissemination and research translation
  - Time saved through pool of "research ready" consumers
  - Greater accountability of public investment in research

- **Deliver needed support to consumers and researchers**
  - Consumers will be readily available for research projects
  - Upskilled consumers
  - Support for researchers to meet increasing expectations that consumer input will be included in research processes
  - Development of consumer engagement pathways for individual research projects, i.e. run researchers' consumer engagement for them

This funding would cover:

- Establish a pool of "research ready" consumers for emerging research projects
- Provide training for consumers
- Delivery of a service connecting researchers to consumers (for researchers)
- Develop a standard set of principles that defines the mutual obligations, rights and roles of researchers and the communities that are the objects or beneficiaries of research
- Consumer and industry online portal of a series of community conversations, research forums and research showcase to recruit interested community members

"It is particularly useful to hear about the experiences and ideas around consumer engagement from other researchers. I am now planning to extend my research and speak to carers of patients with cerebral palsy about their experiences of sleepless nights. I hope this will compliment my research on carer's fatigue" - Robert, clinical researcher

2. Invest in digital infrastructure through the draft Australian Digital Health Strategy to improve equitable access to digital health [$2 million over two years]

> *"Weak governance of digital technologies is causing health inequities and compromising human rights"*[5]
> – The Lancet

The opportunity

Digital health provides opportunities for improved, person-centred consumer healthcare.

Yet rapid digital health uptake is outpacing consumer privacy expectations and inclusive, equitable healthcare access.

Concerningly, vulnerable Australian are missing out and risk being left behind. The Australian Digital Inclusion Index (2021) shows that:
- Digital inclusion increases with education, employment, and income
- There is a marked divide between metropolitan and regional areas
- 11% of Australians are 'highly excluded' and 17% are 'excluded'
- Digital inclusion remains closely tied to age[6]

For example, the Index scores demonstrate the rural/regional and metro divide…
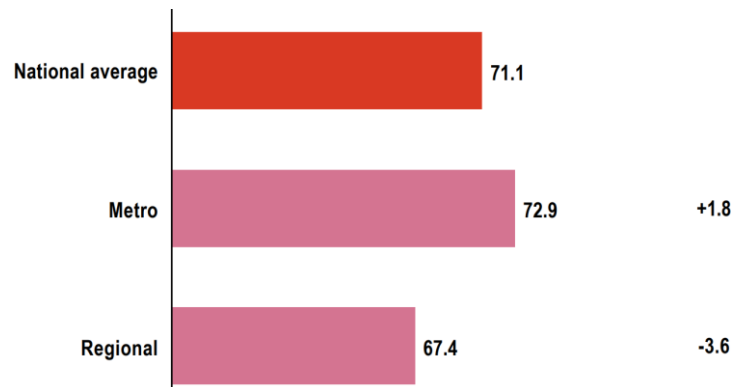
…and the income divide[7]:
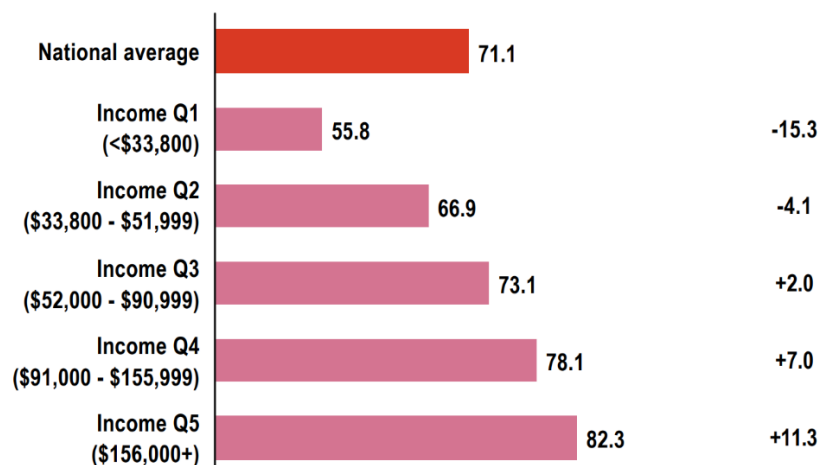
HIC and Safer Care Victoria convened a public forum in June 2021 with 158 registrants to examine the extent and impact of the "digital divide."[8] Key findings included that our system has been extensively digitised and numerous cohorts are facing barriers to digital health access, including those with specific conditions.

We commend the Government for the introduction of Telehealth MBS items during the COVID-19 pandemic and its commitment to making telehealth permanent. The next step is to help ensure Australians have the necessary infrastructure to be able to access digital health.

What are we asking government to do?

HIC recommends the new National Digital Health Strategy (2022-27) reflects the need to address the digital divide, including internet access, social disadvantage, health literacy and other barriers to digital health use.

This is supported by the recent (November 2021) report by the House Select Committee on Mental Health and Suicide Prevention, which recommended:

- "that the Australian Government ensures the next National Digital Health Strategy (2022-27) explicitly addresses barriers to digital access, and includes specific actions for reducing the 'digital divide.'"[9]

In framing and reaching this conclusion, the Committee notes that 'it is critical that services continue to be supported and operate offline and in physical locations, to ensure that the delivery of digital services does not reduce access.'

HIC supports this recommendation and recommends the 2022-23 Budget invests to explicitly address barriers to digital access, including specific actions for reducing the 'digital divide,' broadly defined.

3. **Support health consumers and health practitioners by funding HIC to deliver its training for consumers and services online nationwide [$400K over two years]**

The opportunity

Consumer input strengthens healthcare delivery and is increasingly being mandated (e.g. NHMRC Guidelines[10]).

However, many consumers do not feel empowered to engage in civic discussions about their healthcare.

Health services find 'Partnering with consumers' the most challenging of the National Safety and Quality Health Service Standards to implement.[11] Some staff are still hesitant about engaging with consumers.[12]

Barriers include communication barriers,[13,14] time and cost.[15,16]

Evidence also shows researchers benefit from training courses to best engage with consumers.[17,18,19]

Consumers need to be better supported to feel more in control of their health care,[20] but learning opportunities are difficult to come by for those who are immobile and/or live in rural communities.

What are we asking government to do?

Support consumer engagement by funding HIC to deliver its training for consumers and services online.

HIC is a recognised leader in consumer and community engagement training. We deliver the only accredited courses in Australia.

This funding would be used to refresh HIC's accredited training, but also to deliver new contemporary and interactive content, develop self-paced online modules, and develop the capacity to deliver the training online.

Likely impact

- *Empowered consumers*. Consumers will feel more confident and better-able to engage in decisions about their own – and others' – healthcare.

- *Upskilled practitioners*. Practitioners will feel more confident dealing with consumers and incorporating their input.

- *More equitable training delivery*. Face-to-face training can be difficult for people in rural and regional areas to attend. Online, self-paced delivery provides another, flexible delivery option for people to enhance their skills and confidence.

- *Better healthcare outcomes*. Empowering consumers and better-equipping practitioners helps incorporate consumer needs in healthcare design and delivery. The training helps services meet the second National Safety and Quality Health Service Standard – 'Partner with Consumers.'

This funding would cover:

- Development of new digitally-delivered content
  - for consumers to improve their skills in engaging with health service providers, and
  - for healthcare providers to enhance their consumer engagement skills
- Consumer and provider access to an online platform to host our online training sessions
- Incorporation of a peer-to-peer support tool into the online content.

"This kind of course and the way it is run sparks my initiative to stand up and voice how I think and feel about health care. There were many skills I acquired while completing the course which I have since utilised by engaging with my new representative role for people with disabilities."
– Consumer course attendee

Engaging better with communities

Mark was among a group of around a dozen community engagement coordinators undertaking the Graduate Certificate in Consumer and Community Engagement (10164NAT) at Health Issues Centre.

"It's important for us as an ambulance service to get feedback from people about what's working and what isn't," he said. "We need to talk to people who represent groups and have a broad knowledge and get feedback from people using our services."

"The course has been really good for us because it's giving us a lot of insight," he said. "How we engage people and groups shows us who's representing the group as opposed to when we're talking to someone from the group about their own experiences in isolation – which is a really important distinction."

"I'm feeling really positive about it. It's welcomed."

Tim said he also welcomed the opportunity to walk in the shoes of his stakeholders and also to benchmark his own activity against that of his peers.

"The course takes the perspective of actual consumer advocates and it's so important for us to connect with who our stakeholders are," he said.

Shea said the course had been very practical.

"This course highlights for me the importance of consumer and community engagement," she said.

"The tools we have been given will assist in doing that as we progress in our roles as community engagement coordinators."

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[11] https://www.safetyandquality.gov.au/sites/default/files/migrated/NSQHS-Impact-Report.pdf

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